

May 21, 1976

*patient name
deleted*

This is in response to your letter of April 26th. I am sorry this has taken so long but it has taken some time for me to collect the recent literature on the syndrome. The condition is pretty well understood, as you know, from a genetic standpoint so that the main opportunity that is presented from the standpoint either of research or for trying to provide some practical help, is to attempt a closer study of the details of the condition. I would be surprised if there were not some research dermatologists who would be quite eager to have access to your family for such purposes, but the area is a little bit out of my own kin and so far I have not had too much luck. Dr. Roger W. Pearson has written a bit about the disease and comments that some cellular mechanism - an exaggeration of the normal mechanism of formation of friction blisters - is involved and that "much more refined data on epidermobiology, particularly ~~epidermobiology~~, are needed".

I wonder perhaps if your very best recourse might not be to contact Dr. Victor McKusick of the Department of Medicine at Johns Hopkins University, perhaps with a copy of the present letter. Dr. McKusick is a most eminent medical geneticist with a special interest in diseases that concern connective tissue, and he would certainly be the person among those that I can think of by far the most likely to suggest whether there are further useful steps to be taken at the present time and who might be the most immediately interested. If he does become involved, you might suggest that he let me know and I can send him some of my own bibliographic notes that may be of little extra help to him.

Sincerely yours,

Epidemolysis bullosa

Joshua Lederberg
Professor of Genetics

JL/rr